

Dame Carol Black

Spring is here and our Scleroderma Family Day is planned for May 9th. We do so hope that as many of you as possible will come on this day as we plan to remember with joy and affection Rita Gordon, who was such an important part of the life of our Unit. It is hard to think about the Scleroderma Unit without thinking about Rita. She was there from the very beginning, she gave so much of her own life and personality and we look forward to celebrating this. In addition we have a host of other very good speakers and lots of up-to date information and advice. We hope for very good weather and look forward to welcoming you to the event.

Clinical Care and Research - Professor Chris Denton

As many of you will be aware, our scleroderma and pulmonary hypertension clinics are bursting at the seams, and we are working with the managers at the hospital to improve space and facilities. Of course this will take time but with recent designation by the Department of Health of UCL and Royal Free as part of one of the five new Academic Health Science Centres in UK so we have great hopes for the future. On a similarly positive note we have been reviewing the general outcome of the scleroderma patient group and see that we are now detecting important complications earlier and improving outcome compared with just a few years ago. This is testament to the hard work of all of the team and also to participation of many other specialists and colleagues. We will be presenting a number of studies at the annual Rheumatology congress of the BSR in Glasgow in April.

Clinical trials in scleroderma are critical to progress and we are working hard to contribute here, dependent as ever upon the superb support of our patients. We have been the top recruiter of patients in the recent international pilot study of Glivec (imatinib) in diffuse scleroderma, which had just started when we had the Family day last year. We will have to wait and see whether this drug has been helpful overall but whatever the results of the trial it is very likely that knowledge from the study will help to improve treatment of scleroderma patients in the future.

Laboratory Research - Professor David Abraham

It has been a busy start to 2009 in the Scleroderma and Raynaud's research unit. We have a number of new staff members and have been awarded new grants to continue our research studies. Work from the group has been presented at various scientific meetings both in the UK and abroad.

Research Our research programme remains at the forefront of research in Scleroderma in the world, with work being published in high-impact science journals. We are in the process of organising the 4th International Vascular biology workshop to be held at the Royal College of Physicians in September. This meeting will focus on the cardiovascular complications with a session devoted to pulmonary disease. Exciting new developments include the study of cells from patients at a more global level. This uses state-of-the-art technology, which will provide us with a much broader picture of what is going on in the disease at the tissue level. These studies will bring us closer to understand the disease process and to identify candidate molecule as targets for therapy and future clinical trials. They will also allow us to fully explore their use as biomarkers to more effectively sub-set the disease and assess disease progression and response to currently available treatments.

Where you can help! Our research studies are progressing very well and you can help us with these! Two areas that we wish to expand upon are the genetics of Scleroderma and also to identify better bio-markers to stage the disease and assess response to therapy. To pursue these areas we need blood samples and skin biopsies. We very much rely upon the willingness of patients and their relative to donate these samples. These are the essential raw materials that we use and without them our ability to understand the disease process and to develop new and effective treatments is severely hampered. We have been extremely fortunate in that many people have agreed to provide samples including of course patients but also many members of staff, spouses, relatives and friends. We hope that this will continue to support our valuable studies.

The Research Experience - The research team hope that during the Family Day you will be able to take a little time to visit the laboratories. We are very interested in telling you about our studies and what we do in the laboratory – please pay us a visit!

Research Grants: We have been awarded the project grants from The Rosetrees Trust who continue their support of our basic science work into translational pre-clinical models of scleroderma and The Arthritis Research Campaign has awarded us a research grant to support a study into developing and analysis in vivo models for scleroderma

Specialist Nursing News

A warm welcome to Tanaka who joined the Scleroderma nursing team in February. Louise and Tanaka are working together to cover clinical commitments for the nursing service. Rachel is continuing with her research project looking at digital ulcers in scleroderma and is thoroughly enjoying her new role. We look forward to seeing you on 9th May for Family day.

Pulmonary Hypertension Team

It's nearly summer time and the PH team remains as busy as ever, even with the three of us! We have been out to the satellite clinics and attended National patient focused and medical meetings to continue to develop the services at the Royal Free and locally. We are hoping to recruit a fourth member of the team over the next few months. Clare will be going on maternity leave at the beginning of May; we all wish her every happiness in her new role as a mother!

Thermography update - Kevin Howell

My thesis on thermal imaging is progressing well, and will be submitted by October 2009. Looking forward to seeing you all at Family Day 2009!"

Family Day - Pamela

Scleroderma Family Day is on **Saturday 09 May**. We are all looking forward to this and do hope you can join us. The programme this year, as you can see overleaf, looks really interesting. The raffle is going well - if you would like more tickets do let me know 01273 672686 or pamela.yeomans@scleroderma-royalfree.org.uk



Scleroderma Family Day

Saturday 9th May 2009

The Atrium, Royal Free Hospital, Pond Street, London NW3 2QG

Programme

09.30 - 10.00	Registration and Coffee	
10.00 – 10.20	Appreciation of Rita Gordon	<i>Dame Carol Black & Friends</i>
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10.20 – 10.25	Welcome to Family Day	<i>Dame Carol Black</i>
10.25 - 10.50	Cause and effect – understanding scleroderma biology	<i>Prof David Abraham</i>
10.50 - 11.20	Bowel disease in scleroderma	<i>Dr Nora Thoua</i>
11.20 - 11.50	Eye problems in scleroderma	<i>Sonal Rughani</i>
11.50 – 12.15	Myofascial exercise therapy	<i>Tanya Ball</i>
12.15 - 14.00	Lunch break — discussion groups – see below	
14.00 – 14.30	External Guest Speaker Linking vasculitis and scleroderma	<i>Prof Kuntal Chakravarty</i>
14.30 – 14.50	Scleroderma in Thailand	<i>Dr Revadee Dejthevaporn</i>
14.50 - 15.15	Improving outcomes in scleroderma – 10 year perspective	<i>Prof Chris Denton</i>
15.15	Raffle	

Lunchtime Discussions Groups /Demonstrations

The heart in scleroderma	<i>Dr Gerry Coghlan</i>
Gynaecological Problems	<i>Miss S Tuck</i>
Demonstration of Myofascial exercise therapy	<i>Tanya Ball</i>
Cosmetic Camouflage	<i>Red Cross</i>
Drug information/monitoring	<i>John Farrell/Jay Pang</i>
Massage	<i>Keith Hunt</i>
Education/Nursing	<i>Louise/Rachel/Tanaka</i>
Rheumatology Laboratory	<i>Research Laboratory Staff</i>
Thermography	<i>Mr K Howell</i>